

**Nebraska Early Hearing Detection and Intervention Program
Advisory Committee Meeting
December 11, 2014
Minutes
1:00 pm - 3:12 pm**



Riverview Lodge, Eugene T. Mahoney State Park

Attending:

Members

Nina Baker
Kathy Beauchaine
Amy Bunnell
Linsay Darnall, Jr.
Rhonda Fleischer
Cindy Johnson
Kim-Jae Kang
Jennifer Racine
Colleen Richart
Pete Seiler
Susan Stibal

Guests

Jessica Cook (for Charlie Lewis)
Cole Johnson, EDN
Lauren Liebig-Trehearn (for Stacie Ray)
John Wyvill, Executive Director, Nebraska
Commission for the Deaf and Hard of Hearing

Interpreters

Frances Beaurivage
Jamy Elker

Staff

Jim Beavers
MeLissa Butler
Kathy Northrop

Newborn Screening

Bloodspot Staff

Krystal Baumert
Julie Luedtke

Meeting start time – The meeting was called to order by Committee Vice-Chair Linsay Darnall, Jr. at 1:00 pm.

Open Meeting Act – Presented at the beginning of Advisory Committee Meeting by Linsay Darnall, Jr.

I. Welcome and Introductions

Linsay Darnall Jr, Advisory Committee Vice-Chair for the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program Advisory Committee, welcomed all Committee members, staff, and guests.

II. Review of Agenda

Kathy Northrop proposed that Item X. *CMV Task Force Update* be moved up to follow item VIII. *Report on CMV Conference*. The Committee agreed.

III. Review of Minutes

The minutes from the September 11, 2014 NE-EHDI Program Advisory Committee meeting were distributed via e-mail prior to the meeting and printed copies were available upon request at the meeting. A motion to approve the minutes, as published, was made by Pete Seiler, seconded by Kathy Beauchaine and unanimously approved by the Committee members.

IV. Presentation – Nebraska Commission for the Deaf and Hard of Hearing

John Wyvill, Executive Director of the Nebraska Commission for the Deaf and Hard of Hearing (NCDHH), presented information on the Commission. John stated that the purpose of the Commission was to promote and advocate for Nebraskans who are deaf, deaf-blind or hard of

hearing and to make a difference in their lives. John distributed a brochure on the NCDHH that provided an overview of the services offered by the Commission. The NCDHH works with HearU Nebraska, Lions Hearing Aid Bank, and Sertoma Hearing Aid Bank to help those who cannot afford hearing aids.

Currently, NCDHH is working on Legislative Resolution 517 which addresses the interpreter shortage in Nebraska, as well as the quality and availability of interpreters. The Commission is reviewing recommendations on how to handle this situation and John shared that the challenges they face impacts each of us in the role we play in advocating for the deaf and hard of hearing population. John encouraged everyone to "like" the NCDHH Facebook page and to share stories and successes on the NCDHH Facebook page. Pete Seiler added that the Commission has always been a state agency and they serve individuals birth to right before the grave. There is an average of about 158,000 deaf and hard of hearing individuals in Nebraska. The NCDHH has a large population to serve, so they are fortunate that people recognize the value of the agency.

Jim Beavers asked how many people contacted the agency in 2014. John said the numbers are published in their annual report. http://www.ncdhh.ne.gov/Publications/2013_annual_report.pdf

v. New Member Orientation Manual

Kathy Northrop highlighted some of the changes to the New Member Orientation Manual:

- Editing and clean-up have been done.
- On page 6 an introduction has been added to the section *Nebraska Newborn Hearing Screening Law*.
- On page 18, under the fourth bullet point the following sentence was added: "*Not all individuals who are deaf or hard of hearing can read lips, but for those who can, here are a few tips to make it easier for them to communicate.*"
- On pages 19 and 20 the *Definitions & Terms* section was left in alphabetical order.
- On pages 21-22 the section on *Communication Approaches* was added.
- On pages 24-26 the section on *Resources* was added.

The following changes were recommended by the members and guests present at the meeting:

- Julie Luedtke recommended that page numbers should always be in the same place, either in the center or on the outside of the page. Also, on the NE-EHDI webpage we need to add a section for the *New Member Orientation Manual* to be available electronically to members.
- Colleen requested that on Page 25 under *Statewide Resources* the *Guide By Your Side* Facebook page be added.
- Rhonda Fleisher stated that on Page 25 under *Statewide Resources* the Department of Education needs to be listed separately.
- Susan Stibal stated that on Page 25 under *Statewide Resources*, *Amplify* should be listed, as it is a statewide resource.

Kathy Northrop noted that there is still some cleaning up to do and to ensure that the Resources are consistent between the NE-EHDI website and the Manual.

A motion to approve the *New Member Orientation Manual* with the noted changes was made by Colleen Richart, seconded by Kathy Beauchaine and unanimously approved by the Committee members.

vi. HearU Nebraska/Hearing Aid Bank Update

Lauren Liebig-Trehearn provided the quarterly report for HearU Nebraska, for Stacie Ray, and reviewed the information detailed in the handout.

John Wyvill mentioned that Stacie Ray and HearU Nebraska was featured in the Lincoln Journal Star in April and that the children's hearing aid bank makes a difference for Nebraska families.

Pete Seiler commented on the cost of the hearing aids in the handout and wanted to know why the hearing aids are so inexpensive. Lauren stated that they are able to work out a deal with the suppliers since they buy in bulk. Cindy Johnson added that there is a difference in "invoice cost" and "retail cost." HearU eliminates the overhead costs, so the handout is showing only the invoice cost at the bulk discount. She added that audiologists in private practice can't afford to sell them at the invoice price due to the multitude of costs associated with running a business.

Cindy also shared that she has a patient at Children's who will be celebrating his sixth or seventh birthday soon. In lieu of gifts this year, he is asking for people to make a donation to HearU Nebraska.

vii. Roots & Wings Parent Weekend

Rhonda Fleischer reported on the Roots & Wings Parent weekend that was held at the Lied Lodge in Nebraska City September 26 – 28, 2014. The weekend was funded by a grant through the Nebraska Department of Education. This year there were 19 guest families in attendance, five of whom were Spanish-speaking. As always, the families were very excited to be there and very appreciative to have had the experience. The childcare rooms and childcare workers were kept very busy all weekend.

There were host families again this year. The only host family that returned from previous years were Todd and Stacey Luther. Some guest families that attended in previous years returned to be host families this year.

All families actively participated in the workshops that were held throughout the weekend. The first night they had s'mores and a campfire to get everyone acquainted which was a great way to kick off the weekend.

This year the planning committee booked a separate dining room for all meals so other groups at the Lodge didn't intermingle with the Roots & Wings attendees; they found that it worked much better.

In the future, they are planning to have a smaller Roots & Wings in the spring at Kearney or somewhere in the western part of Nebraska. A tentative date for the weekend is February 27, 2015. There has been discussion about possibly alternating between the eastern and western parts of the state every other year instead of hosting two each year. For now, there are plans to have a fall Roots & Wings in Nebraska City again, so they have reserved the Lied Lodge for the weekend of September 11 - 13, 2015.

viii. Report on CMV Conference

Kathy Northrop and Dr. Rick Kang attended the CMV Conference Sept 26 – 27, 2014 in Salt Lake City, Utah. Kathy stated that there were about 300 participants, mostly parents. There were five concurrent sessions over one and a half days.

Presenters discussed how Utah passed legislation to require that babies who refer two times on the inpatient hearing screening receive a CMV saliva swab prior to 21 days of age. The test is only \$66. Studies have shown that CMV is the cause of late onset hearing loss in about 50% of babies, so that means that about 50% of babies with late onset hearing loss are *not* being identified. From July 2013 – June 2014, 42,336 babies were screened for CMV in Utah. Of those 42,336 who were screened, 245 did not pass, and 163 tested positive for CMV.

Julie asked if their legislation requires prenatal education about CMV. Kathy N. replied that the Utah legislation does require public education. The Utah Department of Health is charged with providing education to daycare providers, health care facilities, school nurses, health educators, health care providers, etc.

Pete asked how many children in Nebraska have CMV. Kathy stated that the data is not tracked nor reported to the Nebraska EHDI Program at this time. However, according to the data reported at the conference it is the number one cause of hearing loss in babies. Pete asked who is responsible for educating parents about CMV. Kim-Jae commented that it is the OB/GYN's responsibility to educate the parents. Members of the CMV Task Force added that the Task Force is discussing the possibility of reporting that information to the NE-EHDI Program, however, at this point there is no method for tracking that data. Kathy B. added that we will talk about this in more detail during the next agenda item.

ix. CMV Task Force Update

Kathy Northrop, Kathy Beauchaine, Cindy Johnson, Kim-Jae Kang and Julie Luedtke are serving on the CMV Task Force. Kathy B. stated that CMV saliva or urine testing has to be completed

within the first 21 days of life. CMV can affect the brain in several other ways, with cerebral palsy being the most common side effect. CMV is a devastating disease. The CMV Task Force met and is highly motivated and interested in finding solutions to this problem. The Task Force plans to gather information on the incidence of CMV to get the numbers together and do background research. Kim-Jae stated that she knows an OB/GYN doctor in Omaha who is interested in joining the Task force. In addition, Dr. Ann Anderson-Berry, a neonatologist in Omaha, is on the Task Force and has contacted an epidemiologist who is also interested in serving.

Kathy N. stated that if anyone wants to be involved to let her know, because getting more people involved will be helpful. Kim-Jae added that the group discussed a lot of information at their first meeting and everyone is very committed and feels that there is a lot of good that can be done in an effort to educate parents and professionals. CMV can be prevented with education which will prevent the heartache the disease causes for families, so this is a worthwhile effort. Nebraska can be the second state to follow Utah with legislation.

x. Report on CDC Grant Meeting

Jim Beavers and Kathy Northrop reported on their visit to Atlanta, Georgia October 15 – 16, 2014 for the CDC Grantee Meeting. Kathy Northrop stated that attendance at the meeting was mandatory so almost all states and territories were represented. Since this was funded by the CDC grant, CDC funds cannot be used for the annual EHDI meeting in 2015.

Jim Beavers stated that the CDC grant funds the EHDI data system. Soon, the CDC will have a “dashboard” available on their website which will display data for each state’s program dating back to 2009. Jim has had a chance to preview this “dashboard” and while he was reviewing it found that the statistics on the 2012 births in Nebraska were above average when compared to other states in all areas except the “identified within 90 days” category.

Jim also stated that at the meeting, Nebraska was one of four states selected to talk to the group about how we use our data and data system so that was nice recognition for our state and program.

Jim shared that there was breakout discussion session about how the CDC should change the way lost to follow-up is calculated. Nebraska is one of many states unhappy with the way the data is figured. Jim will be involved in future conference calls about addressing this issue.

Another breakout session discussed how it’s difficult to get outcome data on deaf and hard of hearing kids, since it is not readily available data. Cindy Johnson asked why there is not information available on outcomes since the Metro Regional Programs and the Early Development Network (EDN) track that data. She asked why the outcomes are not being reported to the NE-EHDI Program. Jim stated that information on which children are verified for services is reported to

EHDI, data on outcomes like social/language skills and academic achievement compared to their hearing peers is not reported.

Amy Bunnell, with the Early Development Network (EDN), stated that EDN is federally required to track three areas of childhood outcomes in early intervention: language, cognitive, and social emotional. Currently, EDN is working with Barb Jackson at the University of Nebraska Medical Center (UNMC), on analyzing this data. The data is reported as a compilation of all children so the outcomes on children who are deaf or hard of hearing are not separated out and to do so right now would not be possible. Currently, all they can do is report outcomes on all children exiting early intervention services. Since they are not federally required to track the data that way, they are not sure if it would be possible to separate it out. There are confidentiality and funding issues.

Cindy stated that through Tracking Infant Progress Statewide (TIPS), at Children's Hospital, she does a six month follow up on all babies at Children's in the NICU and keeps the data in the event that it would ever be useful.

xi. NE-EHDI Statistics and Lost to Follow-up Information – Jim Beavers

Jim Beavers reviewed the handout entitled *January through September 2014 DOB NE-EHDI Status Report*.

Cindy Johnson commented on the category *Hospital Discharge without a Screening* being at 72, and asked why this number was so high. Kathy Northrop and Jim Beavers explained that it could be for a few reasons, one of them being that the hospital's hearing screening equipment wasn't working. When that is the case, the NE-EHDI Program has a loaner that is offered to the hospitals to use until their equipment is working again. MeLissa Butler added that one small hospital in Nebraska discharges all babies without a screening and has them come back within a few days. Krystal Baumert added that some babies are discharged to home on hospice because they medically fragile and not expected to live.

Jim then reviewed the handout *Nebraska "Lost" for DOB 1-1-2010 through DOB 5-15-2014*. This handout shows the progress the NE-EHDI Program has made in reducing lost to follow-up between 2010 – 2014.

Jim reviewed the handout *1-3-6 Stats Report for 2014 DOB*. Jim commented that Nebraska only meets the six month goal by 50%, but if you extend the timeframe by four months then we meet the goal by greater than 60%.

Susan Stibal asked if there will be a Task Forces formed to address the issues with timeliness of evaluations since 50% of them are not being completed within three months. MeLissa stated the Boystown cases for previous years were reviewed and a lot of babies had other major medical issues that prevented a hearing evaluation by 90 days. Kathy Beauchaine added that when the

2011 – 2012 cases were reviewed, sometimes the baby was evaluated within 92 days. Krystal Baumert asked if the NE-EHDI Program has researched what other states are doing to achieve this goal so we can determine if they are doing something that we are not. Kathy Beauchaine said it would be good to reevaluate the data this year. Jim Beavers added that the NE-EHDI Program audiology student, Courtney Smejdir, is doing her capstone on Nebraska EHDI statistics which includes timeliness to the confirmatory diagnostic evaluation to determine if distance is playing a role in delayed evaluations. Julie Luedtke stated that there is a need for services in western and northern Nebraska and looking into this could help make a case for getting services in underserved areas of Nebraska.

xii. Update on NE-EHDI Website

Kathy Northrop stated that the NE EHDI Program website is now live and she has received a lot of positive feedback on it. The challenge now will be keeping the content current and making needed updates. She asked the Committee to let the EHDI staff know if anyone sees anything that they think should be changed.

xiii. Pictures of Advisory Committee Members for EHDI Website Discussion

Kathy Northrop asked the Committee for feedback on having pictures of each of the Advisory Committee members posted on the NE-EHDI Program website. Susan Stibal commented that she doesn't feel that individual pictures of each Committee member is important but perhaps individual pictures of the NE-EHDI Program staff would be nice. The Committee agreed that individual pictures of each Advisory Committee member were not needed for the website.

xv. March 12, 2015 Meeting Change

Kathy Northrop stated that the original spring NE-EHDI Program Advisory Committee Meeting date of March 12, 2015 falls the day after NE-EHDI Program staff returns from the annual EHDI meeting. She proposed that the date be changed to March 19, 2015. The Committee agreed to the date change. A notice will be sent to all Committee members listing the 2015 dates and locations.

xvi. Other

Linsay added that anyone in the Omaha area is invited to attend the Junior National Association for the Deaf bowling party this evening at the Immaculate Conception Church in Omaha.

xvii. Adjourn

A motion to adjourn the meeting was made by Nina Baker and seconded by Susan Stibal. The meeting was adjourned at 3:12 pm.

*Next Meeting – March, 19 2015 – **1:00 pm** at Mahoney State Park, Main Lodge*

2015 Meeting Dates:

- March 19, 2015 (changed from March 12, 2014 due to EHDI Annual Meeting)
- June 11, 2015
- September 10, 2015
- December 10, 2015

Respectfully submitted by MeLissa Butler, Community Health Educator